

3/30/2013

Kate Koustareva
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Senate Committee On Health Care and Human Services
SB 365

Dear Members of the Senate Committee On Health Care and Human Services,

Please support SB365, the Autism Health Insurance Reform bill introduced by Sen. Bates.

Please consider my testimony below when making your decision on this bill.

I have a 9-year old child with diagnosis of an autism spectrum disorder. He was diagnosed at 4 years old. He qualified for special services through our school district, and they placed him into a self-contained classroom with the kids who have similar disorders. At the recommendation of a neuro-psychiatrist, our family enrolled my son in applied behavior therapy (ABA) program. Since my son was enrolled in ABA, he showed significant progress in his language development and social skills; which enabled him at the age of 6 to attend a regular classroom. He is now 9 and needs much less help from the special services at his school. ABA changed the quality of our life, and because of this service, my son can talk, he has friends, and is on the trajectory of growing up to be a functional and independent member of our family and society.

The insurance company denied our request to pay for ABA therapy. ABA therapy was recommended to my son by a few specialists: a Ph.D., neuro-psychiatrist, a Ph.D., developmental psychologist, and an M.D. Despite clear medical necessity and good documentation in place including a few medical reports, PEBB refused to cover this medically necessary service because they chose not to cover autism. I went through two rounds of appeals, and the insurance still denied payment saying our only reserve is court. At this point, I'm bleeding financially. I could not work full-time because I had to take my son to services. At the same time, I had to pay for costly services out of pocket; and as a result, accumulated debt. I can't afford a lawyer to take the insurance to court and the insurance knows it.

I saw how much ABA services helped my son to improve, and even though the insurance denied to pay, our family paid for ABA therapy out of pocket, as much as \$20 - \$30 thousand each year for about 5 years. We went into debt, we saved on everything. My parents thought twice before buying fruit to eat - because they helped to pay for ABA. Even though being a single mom, I work very hard to pay off credit card debt and often don't get enough sleep, seeing my son play sports with his friends outside is priceless. Bottom line, after many sacrifices, we made it, praise the Lord! My heart aches for the kids whose families cannot afford ABA services for their kids. According to the specialists, my son will not need intensive therapy after this year. I hope that the reform will help other kids who will be diagnosed tomorrow and 2-3 years from now, and give those kids a chance to grow up independent and functional. It's really best for those kids, and for the families, and for the entire society.

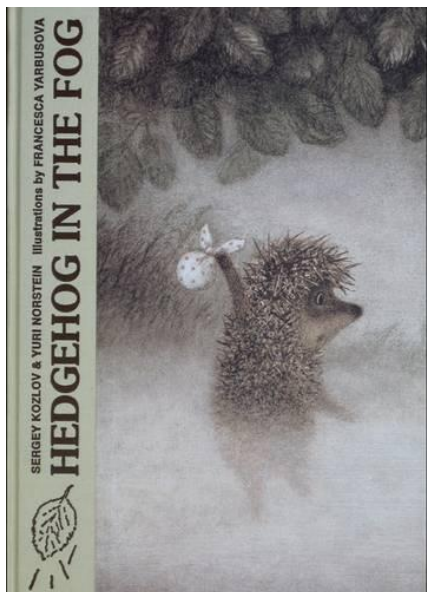
I recently recommended ABA services to another family at our church. I teach Sunday school, and it's amazing to see the little girl getting better and better each week with the right support. This family also pays for ABA out of pocket and I'm proud that they are making this sacrifice for their kid.

There is a prize-winning Russian cartoon "Hedgehog in the Fog." In this cartoon, the hedgehog is lost in the fog. He is confused. Simple things make him scared. He acts inadequately.

I picture autism as a kid lost in the fog. What ABA helps do is... look for the kid lost in the fog, take him by the hand, and walk out of the fog, together, one step at a time, as far as he will go and as fast or slow as he will go... helping him discover the beautiful world we live in and teaching him to understand and love it.

And the timing is critical... the earlier in the childhood ABA services start, the more flexible the brain is to learn... the better chances are to walk out of the fog. Waiting on this bill will cost many people the quality of life... and getting lost in the fog for them may become... forever... please pass SB365.

One in 88 cannot wait!



Thank you,

Kate Koustareva
Autism mom